The better use of personal information – opportunities and risks

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Data and personal information

- good policy is underpinned by good data
- service delivery to individuals can be improved by appropriate use of personal data
- a number of reports on use of knowledge, particularly personal data sets

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Data and personal information

"Countless lives have been saved or improved because of medical research using health information."

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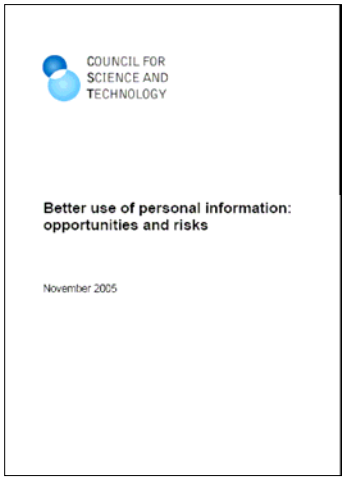
Why now?

- data use and management highly fragmented across Government
- for a typical family there may be over 7 points of contact with government agencies
- timing right to start joined up thinking – large IT projects in progress e.g. Connecting for Health



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Personal data sets are important…

- individuals, society and government will benefit from a more streamlined, coordinated approach
- linkage, access and the effective use of data could all be improved
- huge potential for research and public policy development

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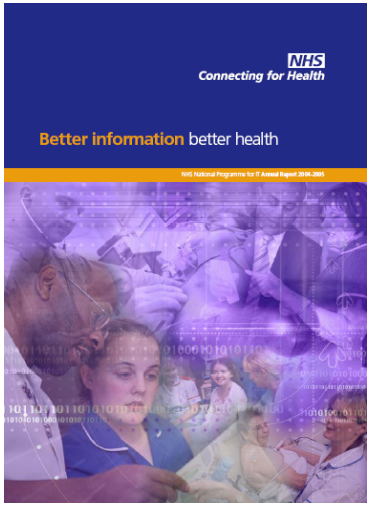
Possible futures in health

- ability to link large datasets
  - demographic
  - health: diet, disease, drugs
  - housing
  - environment
- example of benefits
  - better public health
  - policy based on evidence!
  - personalised medicine



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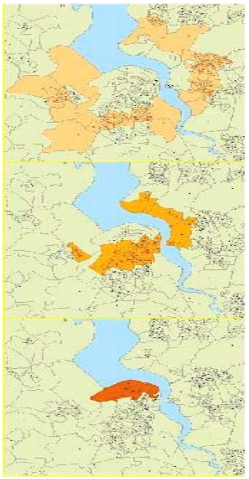
Small Area Health Statistics Unit

- to develop and maintain a comprehensive database of postcoded health data
- to develop and maintain relevant databases of environmental exposures and social confounding factors at the small-area level
- to carry out substantive research studies on environment and health, including studies of socio-economic factors and health
- to respond rapidly to ad hoc queries about unusual clusters of disease, particularly in the neighbourhood of industrial installations



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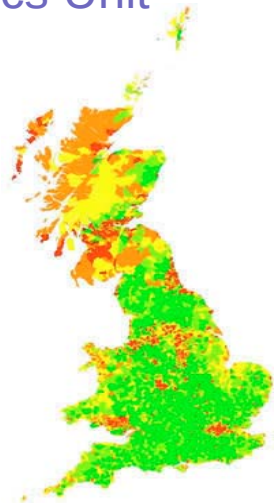
Small Area Health Statistics Unit

- deaths (from 1981)
- cancers (from 1974)
- hospital admissions (from 1991)
- congenital anomalies (from 1983)
- births, stillbirths (from 1981)



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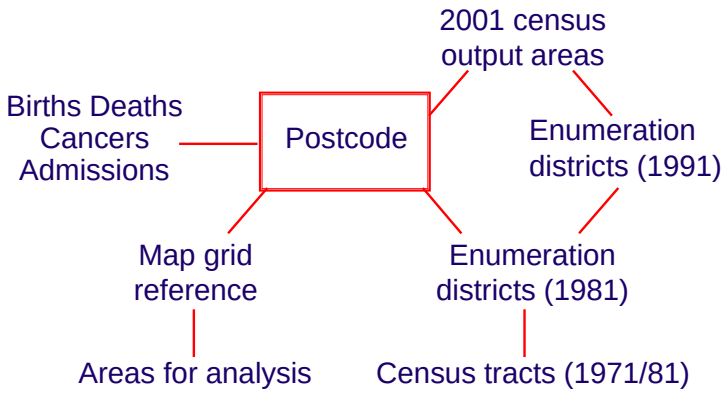
Event data *Population data*



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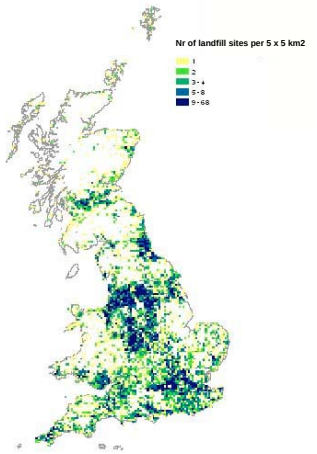
Landfill sites



80% of population within 2 km of closed or open landfill site

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Landfill study

- 19,196 sites in Great Britain
- 9,631 sites were excluded:
  - inadequate data
  - closed before 1982 or opened after 1997
- 9,565 sites included in study:
  - 774 special waste sites
  - 7,803 non-special waste sites

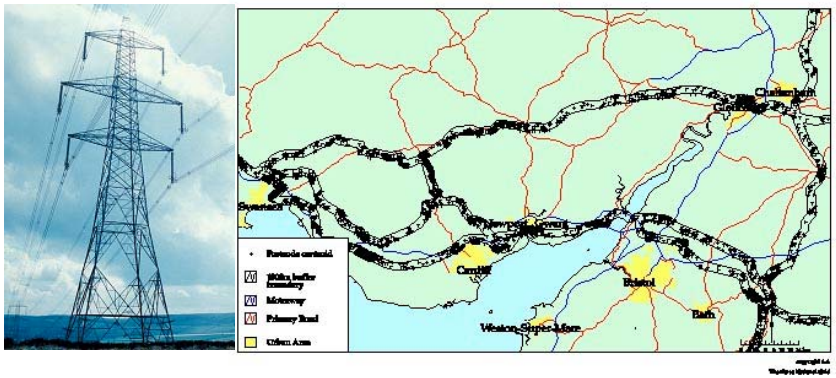
Elliott et al., BMJ 2001;323:363-368

Landfill summary

- 80% of population live within 2km of a landfill site
- small (1-7%) excess risk of low birth weight babies in populations living near landfill sites
- small (1-19%) excess risk of birth defects near landfills
- currently no causal mechanism to explain these findings
- further understanding needed of potential toxicity of landfill emissions and possible exposure pathways to humans

Elliott et al., BMJ 2001;323:363-368

Postcodes within 1 km of overhead high voltage transmission cables



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Drug development

- disease registers
- post approval monitoring
- drug interactions
- identification of side effects

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Risks…

- loss of confidence and trust in privacy
- unauthorised use
- untoward exploitation for commercial gain
- statistical discrimination
- poor quality data
- cyber-terrorism

CST Recommendations (1)

Data access principles

- anonymisation whenever possible, or pseudonymised in the case of linked datasets
- general presumption that access to data should be facilitated where that access is for research or statistical purposes
- appropriate safeguards and transparent governance structures should be in place before personal data can be accessed and used

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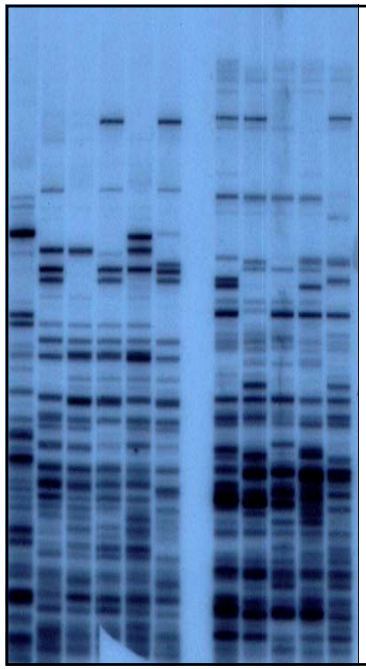

CST Recommendations (2)

Technological research

Government should:

- initiate a technology road-mapping exercise
- stimulate more interdisciplinary R&D
- encourage private sector organisations to share R&D ideas on security modelling
- develop more explicit and proportional confidentiality requirements in its procurement specifications
- promote greater trust through encouraging greater levels of investment by business into IT security

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Regulatory framework

distinguish between:

- use of identifiable information for
  - service delivery
  - law and order
  - research
- use of aggregate personal data for
  - service delivery *eg* traffic flow
  - research

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CST Recommendations (3)

Regulatory framework

Government should:

- provide clarity on how the regulatory regime for data-sharing and data protection operate
- provide legislative changes to promote data-sharing and access
- review guidance issued by different parts of Government to ensure consistency

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CST Recommendations (4)

Public trust

Government should:

- conduct risk analyses and establish risk reduction processes among organisations and individual citizens sharing data
- address real and potential conflicts of interest, and any specific issues – such as involvement of vulnerable groups
- put in place formal data handling policies for researchers or statisticians

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Public trust

- national survey of British public's views (n=2872) on use of identifiable medical data by the National Cancer Registry (funded by CRUK)
- majority *do not* consider the following an invasion into their privacy:
  - confidential inclusion of postcode (88%)
  - confidential inclusion of name/address (81%)
  - receipt of an invitation to a research study, via the doctor after inclusion in registry (87%)
  - all three of the above (72%)
- in addition, 81% of the respondents said that they would support a law making cancer registration statutory

Barrett et al., BMJ 2006; 332:1068-1072

CST Recommendations (5)

Dialogue

Government should:

- sponsor interactions between different stakeholders and the public
- promote understanding on how individual citizens could better take responsibility for managing their personal data
- encourage better articulation of, and debate about, the risk–benefit equation
- determine where responsibilities lie, and how rectification and recompense will be provided in cases where the security of personal data held by government is compromised

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The way forward…

- vision
- trust
- technology
- co-ordination

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